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# BMJ Open After the Liverpool Care Pathway—development of heuristics to guide end of life care for people with dementia: protocol of the ALCP study

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## ABSTRACT

**Introduction:** End of life care guidance for people with dementia is lacking and this has been made more problematic in England with the removal of one of the main end of life care guidelines which offered some structure, the Liverpool Care Pathway. This guidance gap may be eased with the development of heuristics (rules of thumb) which offer a fast and frugal form of decision-making.

**Objective:** To develop a toolkit of heuristics (rules of thumb) for practitioners to use when caring for people with dementia at the end of life.

**Method and analysis:** A mixed-method study using a co-design approach to develop heuristics in three phases. In phase 1, we will conduct at least six focus groups with family carers, health and social care practitioners from both hospital and community care services, using the ‘think-aloud’ method to understand decision-making processes and to develop a set of heuristics. The focus group topic guide will be developed from the findings of a previous study of 46 interviews of family carers about quality end-of-life care for people with dementia and a review of the literature. A multidisciplinary development team of health and social care practitioners will synthesise the findings from the focus groups to devise and refine a toolkit of heuristics. Phase 2 will test the use of heuristics in practice in five sites: one general practice, one community nursing team, one hospital ward and two palliative care teams working in the community. Phase 3 will evaluate and further refine the toolkit of heuristics through group interviews, online questionnaires and semistructured interviews.

**Ethics and dissemination:** This study has received ethical approval from a local NHS research ethics committee (Rec ref: 15/LO/0156). The findings of this study will be presented in peer-reviewed publications and national and international conferences.

## INTRODUCTION

At present, no treatment can alter the course of any form of dementia. Estimated average survival from when the person with dementia first notices symptoms is between 4 and 5 years<sup>1</sup> and from receiving a diagnosis is

## Strengths and limitations of this study

- This study places a high emphasis on family carers and will utilise their experience and knowledge to develop heuristics through a process of co-design.
- Heuristics offer a novel approach to decision-making at the end of life.
- The heuristics developed in this study will be tested in a range of settings.

3.5 years.<sup>2</sup> End-of-life care is therefore rapidly becoming one of the major priorities for dementia care. There are currently more than 670 000 family members and friends caring for people with dementia in the UK.<sup>3</sup> These carers often provide the majority of health and social care, especially earlier in the course of dementia, and without them the professional health and care systems would be likely to collapse.<sup>4</sup>

In England, the government’s End of Life Care Strategy defines end-of-life care as the last 12 months of life,<sup>5</sup> but this can be a problem when supporting people with dementia and those caring for them because it is often not possible to know how their dementia will progress and how other illness may affect the dementia.<sup>6</sup> For this study, the researchers take the view that end-of-life care is not a period of time limited to the final days, hours or weeks of life, but more a period when the person, their family or practitioners recognise that they are dying<sup>7</sup> and this will vary for individuals.

Guidance for practitioners on end-of-life care in England is currently specific guidance only for end-of-life care for people with cancer and not for other conditions, such as dementia.<sup>8</sup> One of the main documents referred to by practitioners at the end of life was the Liverpool Care Pathway which offered a way for practitioners to plan care

for someone who was at the very end of their life, often the final 48 h. The Liverpool Care Pathway involved the withdrawal of unnecessary medication and interventions, and emphasised attention to the personal needs of the dying patient.

Growing media attention highlighted concern about the ways in which end-of-life care was being delivered within England. This culminated in an independent review of the Liverpool Care Pathway.<sup>9</sup> As a consequence, the government announced that it would gradually phase out the Liverpool Care Pathway. Many of the media reports were from family members who felt their older relatives were abandoned or treated differently because of their age. Practitioners' criticisms of the failings of the Liverpool Care Pathway included its over-emphasis on 'paper work' which led to a lack of attention to care. Many considered that these problems were exacerbated by a misinterpretation of many of the key features of the Liverpool Care Pathway, including nutrition, and hydration, together with a lack of training about its implementation.<sup>9-11</sup>

Some practitioners argue that quality care for people with dementia at the end of life is inhibited by its lack of clear structure.<sup>12</sup> The Liverpool Care Pathway provided some support and a structure to guide care practitioners. Its withdrawal following the public criticisms has resulted in a potential 'guidance gap' as well as a potential decline in confidence among practitioners.<sup>13 14</sup> The removal of the Liverpool Care Pathway coincided with the publication of the European Association for Palliative Care's white paper which defined optimal palliative care for people with dementia and their families.<sup>15</sup> This potentially provides the first set of guidance specific for dementia end-of-life care for practitioners but lacks policy endorsement and the controversy over the Liverpool Care Pathway may affect its reception.

Robust scientific conclusions derived from randomised controlled trials or epidemiological studies are too scarce to inform practitioners' decision-making in many areas of practice and many guidelines are not sufficiently based on evidence and are of low quality.<sup>16</sup> Instead, heuristics ('rules of thumb' or 'mental shortcuts') are widely employed to address everyday problems.<sup>17</sup> Typically, heuristics are used in situations of uncertainty, may rely on first impressions, and can occur effortlessly as a form of fast and frugal decision-making that frequently gets the right answer.<sup>18</sup> However, they are also prone to multiple biases and can easily provide the wrong answer; they are assumed by many in healthcare to give second-best outcomes.<sup>19</sup> Nevertheless, heuristics may well be the only solution to managing poorly defined problems where no robust evidence exists and speedy decisions are needed. When uncertainty is high, decision-makers need to use the minimal amount of relevant information—in these circumstances, less is more.<sup>20</sup> Fast and frugal heuristics have also been shown to be more accurate than more complex and sophisticated prediction tools.<sup>21</sup> Heuristics are important to

practise, but to reduce errors and avoid biases they should be discussed, criticised, refined and taught.<sup>17</sup>

'FAST' is an example of a well-known heuristic designed to guide responses to stroke symptoms (standing for Facial drooping, Arm weakness, Speech difficulties, Time to call emergency services). FAST has demonstrated increased accuracy of the identification of patients with stroke.<sup>22</sup> Similarly, PAID may be useful for practitioners trying to understand the causes of challenging behaviour in people with dementia (standing for Pain, Aggravation, Intrinsic to dementia (eg, wandering), Depression/Delusions). The heuristics that general practitioners use in making clinical decisions appear to shape performance more powerfully than any form of formal training.<sup>23</sup>

End-of-life care for dementia can be very difficult for many reasons, not least because of the difficulty in communicating verbally which many people with dementia have towards the end of life. Many practitioners, both those from palliative care backgrounds and those with experience in dementia care, lack the confidence and skills to provide end-of-life care for someone with dementia.<sup>24</sup> This includes practitioners working in care homes where resources, staffing levels and regulatory requirements are limited, and support from the wider healthcare system is variable. End-of-life care for people with dementia is for these reasons often poor, with improvement needed in many areas.<sup>25</sup> There is still limited access to end of life care services for people with dementia,<sup>5 26 27</sup> with a lack of the recognition of pain often highlighted,<sup>28 29</sup> some even believing that people with dementia do not experience pain.<sup>30</sup>

The challenge remains how best to improve end-of-life care in the light of the recent Liverpool Care Pathway review, family and practitioner anxieties and media controversy.<sup>9</sup> One critically important resource is those people close to the person with dementia, often family members. However, rarely have the views and experiences of family carers in their own right been elicited<sup>31</sup> and little is known about the experiences of carers about end-of-life care.<sup>26 31 32</sup> The recent descriptions of poor end of life care surrounding the Liverpool Care Pathway have created an urgent need for health and social care practitioners to make more use of the experiences of families, some of whom experience the dilemmas of care on a daily basis.

The removal of the Liverpool Care Pathway has left a gap in the guidance for practitioners which may need to be filled, as suggested by claims that some organisations are finding it hard to adapt to the Pathway's removal and suspicions that some are simply using it under a different name.<sup>33</sup> We have proposed that this gap could be filled with the assistance of the families of people with dementia, some of whose experiences were similar to those that brought about the demise of the Liverpool Care Pathway. There remains little practice related training in end-of-life care for people with dementia, with dementia apparently still often not being accepted as an

illness which will lead to death, sometimes requiring specialist end of life care input.<sup>34</sup>

Starting with data from 46 interviews with family carers about end-of-life care for people with dementia as a foundation<sup>35</sup> (collected and funded as part of the IMPACT study<sup>36</sup>), our three-phase study described in this paper aims to:

1. Conduct focus groups with family carers both current and former, as well as health and social care practitioners to understand decision-making at the end of life. Data collected from the focus groups, literature and the previous interviews will be synthesised to produce heuristics. These novel heuristics will be discussed, criticised and refined in an iterative process involving experts by training and experts by experience, as recommended by McDonald.<sup>17</sup>
2. Test the use of heuristics with practitioners in five real settings including: one general practice, one community nursing team, one care of the elderly hospital ward and two community palliative care teams.
3. Evaluate the use content, and further refine the toolkit of heuristics through individual interviews, group interviews and online questionnaires.

## METHODS AND ANALYSIS

### Design

This study will use mixed methods and comprise three phases: phase 1 will use input from interviews with families plus findings from focus groups with families and practitioners, and a rapid appraisal literature review to develop a collection of heuristics; phase 2 will test the feasibility of the developed heuristics in real settings and phase 3 will evaluate the heuristics using semistructured interviews and group interviews, finishing by synthesising the learning from all sites to create the final heuristics. Figure 1 shows the project's flow path.

We will develop the heuristics using a standard, well-established developmental approach for creating decision support guides.<sup>37</sup> We have successfully used this method to develop a decision support system for dementia diagnosis and management,<sup>38 39</sup> which was incorporated into the electronic medical records system EMIS (Egton medical Informatics System) after being shown to improve practice in a randomised controlled trial.<sup>40</sup>

A co-design approach<sup>41</sup> will be used to engage carers and practitioners in the identification of important aspects of end-of-life care where heuristics might usefully be applied and the subsequent operationalisation of the heuristics.

Focus groups will be organised for carers and practitioners from different disciplines and the interaction within groups will be facilitated to promote professional creativity and debate around the usefulness and effectiveness of individual heuristics.<sup>42</sup>

The findings from the focus groups and literature reviews will be synthesised, developed and refined into heuristics using a modified nominal group technique with a development group. Nominal groups are potentially powerful learning and development tools.<sup>43</sup> A nominal group process is a structured meeting which seeks to facilitate group or team decision-making about a given problem (generation of heuristics) from a group who are experts in the given field. The process involves an introduction from the facilitator, silent generation of ideas by individuals, group discussion of generated ideas and ranking of ideas to the problem being discussed (in this case, heuristics).<sup>44</sup> They have a particularly useful role in analysing healthcare problems,<sup>44</sup> and can help bridge the gap between researchers and practitioners.<sup>45</sup> A nominal group approach designed for ill-structured problems will be used, to allow for disagreements over problem definition, and to produce potential solutions that overlap or vary widely in specificity. This will require the synthesis process to generate ideas, confirm that it is addressing the same problem, analyse the content of the heuristics and categorise and clarify them.<sup>46</sup>

### Participants and settings

The focus of the study is on end-of-life care for people with dementia in their own homes, acknowledging that some may also classify a care home as their home (community), and on end-of-life care in general hospitals.

*Phase 1 will aim to recruit:*

1. Former family carers and family carers who are currently caring for someone with dementia;
2. Practitioners working with people with dementia at the end of life, including admiral nurses (specialist dementia nurses), general practitioners, community nurses, hospital nurses, healthcare assistants,

**Figure 1** Overview of the project.

**PRELIMINARY STUDY:** 46 interviews with family carers about quality end-of-life care for dementia (Completed)

**PHASE 1: Generation of heuristics of care:** Validation of themes from preliminary study with opportunities for refinement using co-design with focus groups

**Synthesis** of results by multidisciplinary development group including carers using nominal groups

**PHASE 2: Feasibility** of heuristics in real settings (GP surgery, Community nursing team, hospital ward and 2 palliative care community teams)

**PHASE 3: Evaluation** of heuristics through interviews, group interviews and online questionnaires

**Synthesis** of results by research development group and heuristics refined using nominal group

**OUTCOME:** Toolkit to guide the delivery of end-of-life care for practitioners, presented at a symposium for all involved



palliative care teams, social workers, psychiatrists, psychologists and geriatricians.

*Phases 2 and 3 will take place in:*

1. One care of the elderly hospital ward;
2. One general practice;
3. One community nursing team;
4. Two palliative care community teams.

## Recruitment

Family carers for the first phase will be recruited through the Alzheimer's Society and other carers' organisations, such as a local Carers Service and the Carers Trust. We will also utilise the Patient and Public Involvement Forum and the clinical studies groups of the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) and the North Thames Dementia Registry. We will seek help from the DeNDRoN co-ordinating centre, the Comprehensive Local Research Network (CLRN), the education sector and the Central North West London NHS Foundation Trust for recruitment of practitioners and social care employers in the same localities. For the second phase of the study, we will make use of the above networks to recruit a community nursing team, a general practice which has care home responsibilities and a hospital ward. We will seek advice from Marie Curie and members of the research team who have experience of successfully recruiting palliative care teams. All participants will receive a verbal explanation of the study as well as a written copy of the information sheet, and will be given the opportunity to ask any questions. An experienced researcher (ND) will collect informed consent from all participants and the lead site manager/director prior to study participation.

## Procedure

### Phase 1: development and generation of heuristics using focus groups based on data from 46 interviews

At least six focus groups will be conducted with carers, practitioners and other experts. Family carers will be offered individual interviews if preferred. The focus groups will last between 1 and 1.5 h and will be facilitated by a researcher with experience of group facilitation to include:

- Group 1: Up to five bereaved family carers discussing heuristics for hospital care.
- Group 2: Up to five carers currently caring for someone with dementia discussing heuristics for hospital care.
- Group 3: Five–eight practitioners involved in end-of-life care for people with dementia in hospital discussing heuristics for hospital care.
- Group 4: Up to five bereaved family carers discussing heuristics for home care.
- Group 5: Up to five carers currently caring for someone with dementia discussing heuristics for home care.
- Group 6: Five–eight practitioners involved in end-of-life care for people with dementia at home discussing heuristics for home care.

The focus groups will use the 'think aloud' method<sup>47</sup> which encourages people to vocalise their thought process when performing tasks or solving problems. Many have argued that attention is needed for verbalisation of thought processes as this highlights an individual's cognitive-behaviour and information stored in working memory.<sup>47–49</sup>

Each group will be invited to follow the same four stage procedure to discuss and devise heuristics:

Stage 1: Introduction (5 min)—an introduction from the facilitator, explaining the purpose of the study and the focus groups.

Stage 2: Opening the topic (5 min)—the facilitator will introduce quality of care ideas developed from the results of 46 in depth interviews (already conducted) with family carers and a review of the literature.

Stage 3: Discussion (think-aloud) (up to 70 min)—six topics of quality end of care and/or possible topics of heuristics will be displayed on a screen individually for up to 10 min each and participants will be asked to discuss, think about their experience with this topic, what decisions need to be made, and finally what are the right decisions, while verbalising their thought processes. The facilitator will record key ideas on a flip chart.

Stage 4: Summary and close (10 min)—the facilitator will round up the group discussion with a summary of the key topics and thoughts from the group.

A separate development group consisting of ten health and social care practitioners, as well as family carer representatives, will be formed and begin to meet regularly after the first focus group. They will assist with the synthesis of the results and construction of a set of heuristics, acting as a think tank and providing a validation process using a nominal group process as described above.

### Phase 2: feasibility of heuristics

Practitioners will be asked to use the heuristics as a framework and basis when providing end-of-life care for up to 10 people with dementia for a period of 6 months in each setting.

### Phase 3: evaluation of heuristics

#### *Three-month questionnaire and group interviews*

Up to five practitioners from each site will be asked to complete an online questionnaire about their use of the heuristics. This will act as an early indication of the use of heuristics and will enable the research team to identify and address any major concerns, and reinforce the use of heuristics to guide care. We will also undertake group interviews at each site consisting of 5–8 participants, with practitioners to gain a better understanding of whether the heuristics are working and, if not, why. Group interviews keep staff time to a minimum and collect a variety of ideas while allowing for interaction and discussion of these ideas. They will be conducted using nominal group methods (see above).

### Six-month interviews

Following phase 2, semistructured interviews will be conducted with the use of a topic guide on a one-to-one basis with practitioners (5–8 per site) who have applied the heuristics in practice. This will inform the final iterations of the heuristics with the research development team.

### Analysis

Interviews will be transcribed verbatim and thematic analysis methods will be used to analyse the data. Coding will be led by one researcher and checked by two further researchers who will meet regularly to discuss emerging themes to enhance reliability and rigour.<sup>50–52</sup> The development group will be convened and invited to discuss the evaluation and discuss the final set of heuristics using nominal group procedures.

### ETHICS AND DISSEMINATION

The output of this study will be a series of heuristics (rules of thumb) developed using carers' experiences and views, as well as practitioner experiences and opinions, which have been tested with practitioners caring for people with dementia at end of life in various settings.

The findings from this study will be presented in peer-reviewed journals both within palliative care and dementia care journals to target a wide audience which this study will be relevant for. Findings will be presented at national and international conferences, and professional press such as *Journal of Dementia Care* will be utilised to increase the spread of knowledge generated. Finally, a study website will be developed and social media such as twitter and blogs will be used to disseminate findings.

### CONTRIBUTION TO KNOWLEDGE AND PRACTICE

The diversity of end of life care provision has prompted a search for a common language to describe it,<sup>7</sup> while there is greater acknowledgement of the importance of capturing the complexities of provision.<sup>53</sup> End-of-life care for people with cancer is relatively well developed, in terms of its conceptual framework and evidence base.<sup>54</sup> The evidence base to guide practice in end-of-life care for people with dementia is less well developed, although it is now evolving.<sup>55</sup> This study will contribute to the common language, and to the development of practice. The heuristics it develops and tests may help fill the gap left by the departure of the Liverpool Care Pathway.

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**Ethics approval** This study has received ethical approval from both University College London (ID: 3344/003) and from the National Research Ethics Service (ID: 15/L0/0156).

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